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## Young-Onset Dementia: The Child's Experience with Coping

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### Recommended Citation

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# YOUNG ONSET DEMENTIA: THE CHILD'S EXPERIENCE WITH COPING

by

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A thesis submitted in partial fulfillment of the requirements  
for the Honors in the Major Program in Nursing  
in the College of Nursing  
and in The Burnett Honors College  
at the University of Central Florida  
Orlando, Florida

Spring Term 2013

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## **ABSTRACT**

Young onset dementia (YOD) affects not only the person diagnosed, but the family unit as a whole. It is estimated that as many as 500,000 people in the United States have YOD and around 250,000 children are involved in caring for these people. A child of a parent with YOD can begin to experience negative effects when the child begins to take part in caregiving for the person with young onset dementia (PWYOD). Feelings of stress, anger, fear of the future, depression, social isolation, and increasing responsibility of caring for the PWYOD can be felt by children as caregivers. Research shows that children of people with YOD have reported an extreme lack of support and decreased communication within the family. The purpose of this thesis was to examine current interventions designed to improve coping for children of parents with YOD. A review of literature using CINAHL, Medline, and PsychINFO was conducted to gather peer-reviewed articles and journals relating to interventions to help children of parents with YOD cope. However, no studies have discussed interventions specifically for the child. Therefore, information was pulled from 5 studies regarding what children of people with YOD feel has helped them, in their respective experiences, to deal with the stresses of a parent with YOD. Research suggests that individualized care should be provided for these children based on: age, developmental stage, and experience. Children have reported that they cope by spending time away from the home, participating in extracurricular activities, and spending time with friends. Clear communication by all members of the family is also reported to be vital in easing the stresses of caring for a parent with YOD. While children have developed these coping

mechanisms, interventions need to be formally designed and their effect on improving coping examined. Analyzing the experiences of the children with parents with YOD is necessary for clinicians to gain insight into what interventions worked for this population, and what interventions need to be created for further and more individualized support.

### **Dedication**

To my Grandma, my mother, and father: Thank you for inspiring me in my paper and in my life.

To Andrew: Your undying support throughout this paper, Nursing School, and life keep me  
going—I am forever grateful.

## **ACKNOWLEDGEMENTS**

Thank you to Dr. Victoria Loerzel, my Thesis Chair, for guiding me throughout this paper. I thank you for your patience, optimism, and support through this process, and for making me feel proud of this creation.

Thank you to my Committee Members, Ms. Kimberly Dever, and Dr. Denise Gammonley. Your guidance and encouraging words helped me immensely.

Thank you to Dr. Debra Hunt for pointing me in the right direction at the start of this paper. Also, thank you to Dr. Stephen Heglund for getting me started with this process, and for making it feel less overwhelming.

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## INTRODUCTION

Dementia is considered a broad term associated with a decreased mental capability that interferes with daily life. Dementia constitutes a variety of symptoms including a decline in cognitive ability, difficulty with language and communication, reasoning, and problems with short term memory (Alzheimer's Association, 2012). Alzheimer's disease is the most common form of dementia and is most often diagnosed in the elderly. Early onset-Alzheimer's disease is a type of dementia that occurs in people under the age of 65 years. Oftentimes, young onset dementia (YOD) or early onset Alzheimer's disease may be related to family genetics. Approximately 5% of people with Alzheimer's disease are classified as having early onset type (Mayo Clinic, 2011). Young onset dementia will be used as an umbrella term in this paper to describe all of the early onset dementias including young onset Alzheimer's.

Many times, initial symptoms involve problems with short term memory (Nazarko, 2011). As the disease progresses, people gradually experience changes such as cognitive decline, decreased decision making, and loss of social functioning. Loss of social functioning can also be an early manifestation of the illness. In addition, physical manifestations that appear as the disease progresses include losing the ability to walk, speak, or swallow. Young onset dementia is most commonly diagnosed between ages 45 to 65 (Sampson, Warren, & Rossor, 2003). Having a parent or grandparent diagnosed with early dementia or early Alzheimer's can be a risk factor for individuals (Mayo Clinic, 2011).

Accuracy and early diagnosis is imperative for timely treatment, understanding the disease, allotting time for the family to cope, and adequate time to plan for the future. Time

between symptom onset and official diagnosis ideally should be minimal, however, when diagnosing YOD compared with late onset dementia, this is often not the case (van Vliet, de Vugt, Bakker, Pijnenburg, VernooijDassen, Koopmans, & Verhey, 2013; Alzheimer's Association, 2012). Barriers exist that make accurate diagnosing of early onset dementia difficult. These barriers include the slow onset of symptoms, lack of access of resources to specialized health care providers, and denial of symptoms by the person with young onset dementia (PWYOD) and the family (Alzheimer's Association, 2012).

Early in the disease process and as the symptoms of dementia progress, the PWYOD knows, to some extent, the effect the disease is having or will have on the family. This can take an emotional toll on the person and family. Harvey (1998) found that over half of caregivers had a high degree of distress that could be considered a psychiatric illness. Difficulties perceived by family members, caregivers, and children of the person with young onset dementia can be debilitating and can make it more difficult for the family to handle challenges in the future (Cartpentier, Bernard, Grenier, & Guberman, 2010). Thoughts of impending financial insufficiencies can burden the family, especially the PWYOD and the spouse. A report from the Alzheimer's Association (2006) found that many of those diagnosed with young onset dementia are still working when symptoms begin to occur. Symptoms that arise, especially before diagnosis, may often be misconstrued and interpreted as poor job performance (Maslow, 2006). The PWYOD retiring because of poor job performance due to symptoms of the disease, such as from decreased memory due to the dementia, may have poorer results than retiring because of health concerns (Armstrong, 2003).

## **Problem**

Dementia not only affects the patient, but the family unit as a whole, specifically the child and especially when the child is put in the caregiving role. According to the life course perspective, timing of significant life events impacts individuals and families. When life events happen too soon or at a different time than expected, it is considered out of sequence for the family. YOD is considered an off-course event for the family (Gelman & Greer, 2011) which can lead to children experiencing a variety of problems such as: difficulty coping, family conflict, emotional stress, psychological stress, or social decline.

A child of a parent with YOD can begin to feel the effects of role reversal when the child begins to take part in caregiving for the parent. Feelings of stress, anger, fear of the future, depression, social isolation, and increasing responsibility of caring for the PWYOD can be experienced by children as caregivers. The child could end up feeling embarrassed to bring friends over to the house where their parent with young onset dementia lives (Armstrong, 2003). This creates stress for both the child and the parent with YOD including stress on their relationship and the child is often affected psychosocially (Luscombe, Brodaty, & Freeth, 1998). The child might wonder whether or not they themselves will become affected with young onset dementia (Armstrong, 2003). Young children may fear that they will “catch” the disease from the affected parent (Alzheimer’s Association, 2012). Many times, children also report feelings such as: becoming a grown up too soon, grieving for the affected parent, emotional detachment from the parent with dementia (Svanberg, Stott, & Spector, 2010).

Studies by Luscombe *et al.*, (1998) and Harris and Keady, (2004), found that there were significant changes in family behavior. Family conflict resulting from the dementia was recognized by 41% of caregivers of the PWYOD and 51% of the caregivers reported that their children had been involved in conflict such as arguments or frustration with the affected parent.

It is estimated that as many as 500,000 people in the United States have YOD (Maslow, 2006) and around 250,000 children involved in caring for these people. Most interventions for dementia patients and their families are geared toward people with older or late onset dementia. As a younger people are being diagnosed with YOD, new interventions should be studied, evaluated, and implemented for this population, as well as for the child of the PWYOD.

Research has been conducted to assess the specific needs of children and spouses of the PWYOD. There have been studies of children as caregivers and studies of people with early onset dementia but very few combining the two. Exploring the state of families, specifically children of the PWYOD, and identifying interventions for these families affected by YOD is imperative to prevent problems later in life, particularly unmet developmental milestones and psychological stress. There is a sufficient knowledge gap of interventions for this particular population. Lack of sufficient interventions for children of people with YOD can lead to emotional, psychological, and social conflicts of the family unit as a whole.

## **Purpose**

The original purpose of this paper was to review the existing literature for interventions to help children cope with a parent with YOD. Since no true intervention studies were found, the purpose of this paper became: to review the existing literature for interventions and means of coping for children who are caring for a parent with YOD. The secondary purpose is to make recommendations for nurses to be able to better support and help children of parents with YOD cope with the stresses associated with caregiving.

## **Method**

A review of existing literature was conducted related to the child caregiver of the PWYOD. Articles and information were found using the Cumulative Index of Nursing and Allied Health (CINAHL), Medline, PsychINFO databases. This search included peer-reviewed articles and journals that included interventions for children and spouses participating in caregiving for PWYOD. Articles were excluded if they were not available in full-text English, if they were published before 1990, if the article centered on people with older onset dementia, or if they were genes/genetics, medication, or risk factor based studies. Articles were also excluded if they were a mixed-aged population (including both older and young onset dementias). Key topics searched included: “young onset dementia”, “early onset dementia”, “children”, and “family”. Other information was gathered from accredited associations or organizations pertaining to young onset dementias.

## **FINDINGS**

A search using CINAHL, Medline, and PsycINFO was conducted. Key terms in the first search were: “young\* onset dementia” OR “earl\* onset dementia” OR “young\* onset Alzheimer\*” OR “earl\* onset Alzheimer\*” AND “child\*” which produced 46 articles. This search did not yield any results on specific interventions for the child. However, four articles contained information relevant to the experiences of children coping with a parent with YOD. Another search used the same search engines with the following keywords: young\* onset dementia” OR “earl\* onset dementia” OR “young\* onset Alzheimer\*” OR “earl\* onset Alzheimer\*” AND “famil\*” OR “families” NOT “gene\*” produced 70 articles, with 1 article that was relevant to how families coped with a family member with YOD. In total, five of these articles were relevant to coping experiences of the child as a caregiver for a PWYOD.

*Table 1: Search Strategy*

<b>Databases Searched</b>	<b>Key Terms Searched</b>	<b>Number of Articles Found</b>	<b>Number of Relevant Articles</b>
CINAHL, Medline, and PsychINFO	“young* onset dementia” OR “earl* onset dementia” OR “young* onset Alzheimer*” OR “earl* onset Alzheimer*” AND “child*”	46	4
CINAHL, Medline, and PsychINFO	“young* onset dementia” OR “earl* onset dementia” OR “young* onset Alzheimer*” OR “earl* onset Alzheimer*” AND “family” OR “families” NOT “gene*”	70	1
<b>TOTAL:</b>		<b>116</b>	<b>5</b>

For the purpose of this paper, an intervention will be defined as an action any third party can take to try to help the child, family, or PWYOD. There were no true randomized intervention trials specifically for the family and especially not for the children of the PWYOD. Therefore, studies were searched regarding what children of people with YOD feel has helped them, in their respective experiences, to deal with the stresses of caring for a parent with YOD. Information was pulled from 5 studies regarding what can help children of people with YOD deal with caring for a parent with YOD. Articles included: one analyzed case study, one article that examined the experiences of the creators of a support program, and three articles that explored, in some aspect, the coping experiences of children living with a parent with YOD. Few studies have focused on interventions specifically for the child.

## **Articles**

Gelman and Greer (2011) conducted a review of literature of children's needs and experiences with YOD and qualitative analysis of case studies that examined the effects of caring for a parent with early onset Alzheimer's disease (EOAD), a common form of YOD. A total of three case studies were included but only one fit the criteria of this paper.

The family had participated in "a counseling and support intervention for Latino family caregivers of persons with AD [Alzheimer's Disease]" during which the New York University Caregiver Intervention (NYUCI) was implemented. This intervention was made up of three parts: six individual or family counseling sessions, participation in a support group, and ad hoc counseling with referrals based on the needs of the caregivers. The family consisted of a father



with YOD (50 years old), a mother (40 years old), a daughter (16 years old), and a son (12 years old). The goal of these interventions was to provide education and social support for the caregiver (spouse) and to promote communication and problem solving abilities within the family.

At the end of these sessions, the daughter reported that she was able to recognize and communicate her feelings regarding the stresses and changes she was experiencing associated with her father and his YOD. However, the son had more difficulty understanding the dimensions of his father's YOD and reported feeling "sad and angry" a lot of the time. The son did well in school and studied as a means of coping but had experienced weight gain because of the stresses from the changes within the household. Lastly, the mother became aware of the stresses that her daughter was going through and had incorporated a social support system for herself. The father's outcomes were not mentioned.

A qualitative study by Svanberg, Stott, and Spector (2010), used in-depth interviews with 12 children ages 11-18 to address three main objectives: to determine if children who care for a parent with YOD could be compared with other caregivers, to identify the positive and negative outcomes of caring, and to explore what can help with coping and resilience in children dealing with a parent with YOD. The twelve participants in the study were under the age of 18, had lived with or were currently residing with a parent with YOD and were aware of the diagnosis. Six male and six females were recruited from nine families in the United Kingdom. The study utilized grounded theory methodology with three quantitative measures including: the Recent

Mood and Feelings Questionnaire (MFQ), the Zarit Burden Interview (ZBI-short), and the Resilience Scale (RS) to supplement the qualitative interviews.

Most of the children interviewed felt that they did not need more information about dementia itself, but expressed how important it was to have honesty from both parents throughout the course of the disease process. In addition, most children interviewed minimized their roles as carers and described themselves as “just helping.” However, all of the children interviewed took on tasks such as: “checking in” with the parent, keeping the parent company, provided personal care, and emotional support for the parent with YOD. Some participants reported that spending time alone was effective in helping them hide their feelings or to better cope with the emotional effects of living with their parent with YOD. Most of the children reported that spending time with friends and spending time at school helped distract them from their every-day situation at home. In addition, having friends that verbalized emotional support for the child such as “I’m here for you if you need to talk” was seen as extremely important to the child.

Five of the children that were interviewed reported using services that helped ease the burden on the family such as counseling. When asked what services would have been helpful for the children, the majority reported that respite services would have helped alleviate the burden on the entire family. The children also reported that contacting or talking with other children who have had similar experiences with a parent with dementia would have been helpful. Findings of this study concluded that children and young carers of a parent with YOD and their families need more support. An appearance of the children being mature and comfortable with caring for the

parent with YOD may not mean that they are coping with the changes experienced because of the impact of YOD on the family.

Nichols and colleagues (2013) conducted a study to gain insight into the needs and experiences of young people who cared for a person with frontotemporal dementia. The purpose of exploring these experiences was to formulate a website designed to support young carers of people with dementia and to help them cope. For this study, two focus group semi-structured interviews were conducted. The group interviews were tape-recorded and thematic analysis of the interviews was completed. No interventions were implemented. The young carers interviewed were 8-19 years of age and identified themselves as caregivers of someone with a type of frontotemporal dementia. Of the 14 young carers, 12 of them had been involved in caring for a mother, father, or stepfather with dementia and aged 11-18. A limitation of this study was that the ages of the parents with dementia were not provided and this makes it difficult to categorize them as YOD parents. However, because the participants in this study were children living with a parent with dementia, this study was included in the findings. The following themes were identified: living with a parent with dementia, caregiving, coping, diagnosis, relationships, support, and symptoms.

The first theme included many negative emotional aspects associated with living with a parent with dementia such as anger, embarrassment, and fear, but also expressed several positive emotions. The theme of caregiving relayed the particular ways that they had participated in caregiving which resulted in physical and emotional tolls on the child. The third theme, symptoms, summarized the difficulty in communicating with the parent with dementia along

with the parent's decreased insight and judgment. All of the interviewed children had reported that they preferred for the diagnosis to be relayed sooner, rather than later, and that each child should be informed of the diagnosis based on their "age and maturity." Children had also spoken about the theme of changing relationships with the parent with dementia as well as with the healthy parent.

While the authors had found 7 themes, the area of interest for this paper was how children coped and received support; therefore, "coping" and "support" will be the only theme discussed in greater detail. The children interviewed had talked about coping strategies they had used to deal with the parent with dementia, relationships with the "healthy parent," and the impact that the dementia had on their families. The children interviewed expressed that spending time with the parent with dementia and talking about memories and "pleasant topics" had helped them cope. The children also gave examples of family activities that helped ease the burden, such as: having basic conversations, watching television, going on walks, and going on family vacations. Some of the children interviewed expressed that participating in extracurricular activities helped "channel their energy outside the home" with activities such as: sports, dance, choir, and volunteering.

The children also talked about the support that they had received as a result of their parent having dementia. Most children depicted their "healthy parent" as the main provider of family support including: presenting information, emotional support, and stability. The majority of the children interviewed had expressed that speaking with a friend as a means of support was helpful to them because they were simply willing to listen, regardless of the fact that most of the

children's friends had little understanding of dementia. When asked if the children wanted to be present at doctor's appointments, most said they would rather not because they did not think they could cope with what they would hear. When participants were asked about receiving support in-person or through technology, most children expressed that in-person conversations were better received.

In regards to support groups, the participants in this study suggested that smaller support groups and support groups organized by age would be more helpful. Many of the children thought that it was helpful to have a discussion about dementia and their experiences and found it "helpful to get things off your chest." Some suggested that online forums for discussion with other kids about their experiences would be helpful, especially since "more kids are into computers" and that it might be more comfortable typing about it rather than talking about it."

Allen, Oyebode, and Allen (2009) conducted a study to examine the outcomes of children who have a father with YOD. This study used grounded theory. Interviews were 45-90 minutes in length and participants were asked open ended questions that incorporated personal stories and experiences from their perspectives. Twelve young people between the ages of 13 to 24 years old in the United Kingdom were interviewed. These young people were living in the home of or were consistently involved in the lives of the parent with YOD. Every participant in the study had a father with YOD. Ten of the children lived with both parents at the time of the study and two of the children had fathers with YOD in a "care home." These interviews were coded into five main themes: damage of dementia, reconfiguration of relationships, strain, caring, and coping, with the theme of "one day at a time" in each of the categories. Although the authors

had coded these themes, the topic of interest for this paper related to ways that children cope with YOD and any support received; therefore, the themes “coping” and “one day at a time” will be discussed in greater detail.

In regards to the theme of “caring” for the parent with YOD, some of the young people reported that the family had received help for the PWYOD from either Social Services or had personally arranged for help. The participants generally felt that having some help took away some of the emotional and psychological stresses of caring. One of the participants stated that the family received help for the father with YOD in the form of a male carer coming to the house. The participant said that this helped the family to not only for care of the father with YOD, but to have someone for the healthy parent to “talk to about things that she...doesn’t want to talk to the children about.” It was also found in one of the interviews that more information made it better to plan out the care of the father, and relieved some tension for the whole family.

The theme of coping was a topic area of interest in the study and for this paper. Ways in which the young people reported coping included both positive and negative aspects. Positive ways of coping included support involving siblings and talking with friends. Other ways of coping included distraction, such as going to school. Normalizing was also reported as a useful coping mechanism for the young people interviewed. Ways of normalizing included daily activities together such as having meals as a family. Taking it “one day at a time” was reported as being helpful because looking too far into the future was often overwhelming for the young people. There were many negative coping mechanisms reported in the interviews, including denial, drinking (sometimes excessively), and smoking. In one account, methods of self-harming

were reported, including the intention of suicide. It was concluded that young people are at risk for negative impacts when having a father with YOD and more support should be provided for children of a parent with YOD.

Arends and Frick (2009) created a support group program geared towards people who were living with a person with early onset Alzheimer's disease (EOAD) entitled "Without Warning™." The article describes the authors' (group leaders) experiences with running this support group. Since the start of the program, the group leaders have led a seminar, 57 family meetings, 3 events for children less than 18 years of age, and social events for the family. The purpose of this article was to explore the development of a program geared toward people with YOD and their families including spouses and children and to implement changes to the program based on the feedback from the participants. The purpose of implementing this group was to support each member of the family unit throughout the progression of the EOAD. Throughout several years that this program has been offered, family members and those with early onset Alzheimer's have given feedback and thus helped develop a more family-oriented program.

There were numerous group discussion topics geared toward the family composed of the person with EOAD, the spouse, and the child. Topics geared toward the child included: fear of the future, will this happen to me, life is more restricted, impacts of the child's social life, emotional troubles, hardship in school, loss of "mom and dad" roles, loss of childhood, taking care of the diagnosed parent, and anger issues among several others. During group discussion meetings, family members and people with early onset Alzheimer's split into separate groups for

60-85 minutes. A survey was conducted for family members to provide opinions about group size. Through that survey, it was found that family members preferred smaller group sizes.

For this support group, meeting location, schedule, and ending on time were important factors. It was found that it was in the best interest of the group members to meet in an easily-accessible building that included an elevator and that was well-lit. Meeting times were scheduled to be from 10am to noon, mostly because “morning hours are typically better for individuals with EOAD.” Separation of the groups was an important concept because it was more beneficial for the family of the person with EOAD to be able to discuss issues separate from the person with dementia. Part of the meetings were held with both groups and part of the meetings separated the people with EOAD from the family. Smaller groups were also implemented to attempt to allow all members who want to speak to do so. Ending the meetings on time provided less of a chance for the person with EOAD to wander away from the family and may prevent them from becoming anxious when waiting for their family.

It was important to maintain group dynamics within the support group. In the groups for people with EOAD, it was important to consistently have more than one staff member present at all times but was vital to have one main group facilitator to maintain consistency and routine. Cueing the person with EOAD when being questioned or when participating in group discussions proved helpful in maintaining group discussion flow. These people with dementia often forget that it is their turn to speak so they may need some prompting.

The group sessions for family members were conducted in the traditional support group format. It was found that little prompting for the family members is needed. The families could



often easily direct conversation on their own. As the group became larger, fewer people got to speak and not everyone got as much out of the sessions as they would have liked. So, according to the authors' experiences and the experiences of the family, the best size of a small group was 8-12 members. Family members found it extremely important to learn from and gain support from other members in the group.

## **DISCUSSION**

A total of 5 studies were found to have been relevant to the experiences of coping with a parent with YOD. Three of these studies focused on children and what helped them cope with their experiences, one study explored the experiences of staff who had developed a program for PWYOD and their family members, and another focused on the family unit as a whole and included children. None of these studies provided a true intervention that measured outcomes directly. However, the information obtained is highly valuable in order to gain insight into what coping mechanisms worked for children of a parent with YOD and to create new interventions in the future.

Two articles (Gelman & Greer, 2011; Arends & Frick, 2009) inferred that group support is considered a means of helping the family cope with living with a person with YOD in ways such as supporting open communication and speaking with people with similar experiences. However, incorporating problem solving strategies and effective communication strategies proved helpful in both studies. In the analyzed case study, (Gelman & Greer, 2011) two children in the same family received the same support but perceived it differently since the ages and genders of the children were different. Support should be individualized since each child can react differently to the same experience and all interventions may not work for all age groups.

One of the studies, Arends and Frick (2009), had implemented a program geared towards supporting the entire family unit that was affected by YOD, including the spouse and the child. The authors described specific group discussion topics that were of interest to the families and best practices utilized for their group. This is valuable because the people toward whom the

program is geared helped develop this program by providing advice in terms of improvements for the group. Now, smaller group sizes, little prompting from the facilitator, and morning meeting times were changes that were implemented based on the group consensus.

In two studies, children wanted open, honest communication from both parents (Allen, Oyebode, & Allen, 2009; Svanberg, Stott, & Spector, 2010). Children in one study reported that being provided more information helped them to plan better for care of the parent with YOD (Allen, Oyebode, and Allen 2009). However, some did not want to attend doctor appointments because of the fear that too much information would be difficult for them to handle or because they simply did not want any more information on YOD (Svanberg, Stott, & Spector, 2010; Nichols, et. al, 2013).

Three studies found that children wanted to spend time with friends, at school, outside of the home, or engaged in extracurricular activities in order to distract them from the everyday stressors (Svanberg, Stott, & Spector, 2010; Nichols, et. al, 2013; Allen, Oyebode, & Allen, 2009). Two articles found that children perceive comfort in spending time together as a family doing “normal” activities such as watching television or going on walks (Nichols, et. al, 2013; Allen, Oyebode, and Allen 2009). Taking it “one day at a time” and not looking too far into the future was a big theme in one study (Allen, Oyebode, and Allen 2009). Normalcy may help the child perceive the family as a still-functioning unit and may also help maintain relationships longer. By participating in simple activities as a family, stress may be reduced and the child will still be spending time with the PWYOD and other members in a more normal way.

Four studies found that outside help, in the form of respite care, support groups, and counseling would be very helpful for the family unit, including children (Svanberg, Stott, & Spector, 2010; Nichols, et. al, 2013; Allen, Oyebode, & Allen, 2009; Arends, & Frick 2009). It was also reported that many adolescent-aged children may benefit from an online support group (Nichols, et. al, 2013). Other advantageous interventions for the children caring for the parent with dementia included providing education about dementia, support for the child, support for all members of the family in the home, and support targeted for specific, individualized age groups (Nichols, et. al, 2013).

Arends and Frick (2009) found that some children whose families had received physical help, in the form of direct contact care with the PWYOD had reduced emotional and psychological stress. It was also found that home care had eased the caregiving burden for one family in the study. By referring respite care for the PWYOD directly, the family may reduce stress.

Several unhealthy ways of coping were reported in a study by Allen, Oyebode, and Allen 2009. Drinking (alcohol), smoking, and self-harm were ways in which young people coped with having a parent with YOD. These means of coping should be prevented. Without direction or healthy support systems in place, children may become misguided and resort to coping mechanisms that are detrimental to their well-beings. If proper assessment of all members of the family, including the child, is completed, then these unhealthy means of coping can be prevented or discontinued.

## **RECOMMENDATIONS**

### **Recommendations for Nursing Practice**

Nurses will be interacting with PWYOD in various healthcare settings. The assessment is often focused on the person with YOD, but the assessment of the family, including the child, is imperative as well. By assessing the child, the nurse may be able to determine additional needs of the family or child and the nurse could make recommendations. The family may confide in the nurse on a more personal level, for example, about what life was like before the diagnosis and progression of the disease and what kinds of stresses occur. This may further aid the nurse in individualizing care. When making recommendations, the nurse should also consider age, developmental stage, and experiences of the child since not all interventions will work for all children. Nurses should consider individualized support based on these assessments. Assessing the caregiver and child for stress, how they deal with stress, asking how the child feels about the future, and discussing plans for caring for the PWYOD are important in making proper and specific referrals.

The nurse or clinician should learn who the primary caregiver of the PWYOD is and also who is living in the home or surrounding the PWYOD in social aspects. Using this information, the nurse or healthcare professional can assess how the family has functioned in the past in comparison with its present functioning and thus determine the change over time. By understanding these changes, the nurse can provide more effective interventions that are

specifically geared toward that family or child such as respite care or financial/legal planning for the future.

School nurses may also prove to be valuable to the support system for the child of the parent with YOD. Nurses in the child's school may or may not be aware of the diagnosis of the affected parent. If the nurse is aware of YOD being present in the home, she can make referrals to support groups or respite care that may be utilized by the child's family. The school nurse may also be able to identify any changes in school work or social decline of the child. Identifying negative coping or regression may be important in order to prevent further decline in the child.

### **Recommendations for Education**

Nurses should continue to be aware of how YOD affects the family unit, specifically the child. Based on the findings of this review, there is a need for children to be adequately, but not overly, informed and educated on issues relating to the parent with YOD. Nurses should recognize that although open communication with children is preferred, too much information may cause increased stress for the child.

Oftentimes, caregivers of people with YOD receive information and resources from healthcare professionals. However, child caregivers tend to receive resources from their parents. If the parents are not aware of a problem or if they do not know that resources are available, then the problem may lie with the parent's lack of information *and* lack of resources. As a result, there is a strong need for the parents of the child caregiver to be more informed in order to provide means of support for the children.

The Alzheimer's Association recommends that the first step to solving problems pertaining to those with YOD and their families is to increase awareness of the problem. Education for doctors and other health care professionals of the prevalence and symptoms and the need for accurate diagnosis is vital to attempting to identify solve problems relating to the family. Through early and accurate diagnosis, families may have more success in planning the care of the PWYOD and may be more successful in attempting to cope with the diagnosis of YOD themselves.

The Alzheimer's Society also provides information on how to talk to a child or young person about a family member with YOD. First and foremost, having open and honest communication about the disease and what changes occur within the family is imperative. Parents are advised to check-in with the child regarding feelings about the changes associated with YOD. Finding ways for the child to be involved in the care of the parent with YOD can help normalize the changes such as: going on walks, playing games, and talking about pleasant past memories.

Misinterpretation of the terminology of dementia or Alzheimer's diseases may be confusing for non-specialized health care workers, the person with YOD, their families and children. At times when the terms dementia or Alzheimer's disease are used, thoughts are often misdirected towards the elderly population. Many research studies focus on experiences of PWYOD and their families or "carers" but did not specify who, within in the family unit, was participating in the studies.

## **Recommendations for Research**

There is a strong need for further research regarding interventions for the family unit and the child of the PWYOD. More research should be done to develop interventions to help PWYOD and their families cope with the disease process. There is a sufficient amount of studies identifying the problems experienced; now the problems should be explored further and interventions should be developed to assist children of PWYOD. The coping challenges that have been identified in this thesis may lead to refining adequate research variables and topics in order to design possible interventions for this population.

Further research is needed to develop counseling and memory services that aid the PWYOD and the family in communicating its plan of care with each other. Though children may want open communication, the timing of how and when to inform the child about the disease should be investigated. Exploration of respite care, support groups, and family interaction, specified to the younger-onset dementia population, should be investigated as well. Interventions specifically directed towards children participating in the care of the PWYOD should be examined to prevent restriction of social development and stress. When examining this population, the interventions implemented should be clearly defined and should also be responsive to the needs and preferences of the children and family members. It is imperative that children of people with YOD get the support that is needed.

Based on the results of this literature review, there was a limited amount of interventions for this population. More research should be done regarding interventions for the child of the



PWYOD. Research should also be focused in the United States where this problem can be implemented into the U.S. healthcare system more easily.

## **LIMITATIONS**

There were few studies found that specifically investigated interventions for PWYOD and the family. No interventions were examined empirically for a child with a parent with YOD. Although some studies have suggested interventions or best practices regarding resources for children coping with YOD, it is unknown how effective these recommendations will be. Most of the studies in this paper utilized qualitative methods with selective sample sizing. When memory services, support groups, or counseling were used, details on what information was given or discussed was very vague and may make it difficult for clinicians to implement these interventions in practice. These very general suggestions and the fact that there were no ways of directly measuring the outcomes make it difficult to determine which resources work best when implementing these interventions.

Only three of the five studies relied on direct interviews and experiences from children of parents with YOD. Although these three studies provided a valuable perspective on the problem, they also illuminate the fact that there is such a limited number of studies for this population.

One study by Arends and Frick (2009) reviewed the experiences of the authors who had created a support group for those with YOD and their families. The authors had administered surveys that addressed preferences regarding aspects of the support group, but a limitation of this study was that there was no specific data collected and no direct measurement of whether or not this support group had truly helped the families with coping.

## **CONCLUSIONS**

Young onset dementia is a growing problem both in the United States and all over the world. This disease not only affects the person diagnosed, but the family unit as a whole, especially the child of the PWYOD. Potential problems and setbacks can occur as a result of role changes that may happen within the family including conflict between family members, social withdrawal, and emotional stress. Since no true intervention studies were found, coping experiences of the child of the PWYOD were sought after in this literature review. Based on the findings, a limited number of studies were found regarding these experiences, indicating that more research should be conducted for this population. Clinicians and nurses should include the assessment of the caregiver of the PWYOD and especially an assessment of the child. Children of a parent with YOD need additional support to cope with the added stresses. Individualized care is an important element of support to keep in mind when offering resources for the child. While children have developed certain coping mechanisms on their own based on their experiences, interventions need to be formally designed and their effects on improving coping should be studied further.

*Table 2: Table of Evidence*

Articles	Participants	Study Design	Interventions	Key Findings
Allen, Oyeboode, and Allen (2009)  Having a father with young onset dementia.	12 young people aged 13-24 who had a father with YOD, based in the United Kingdom	Qualitative interviews which were 45-90 minutes long. Open ended questions were asked and grounded theory was used to guide the study. Interviews were coded into themes and further analyzed.	None.	<p>-Having some form of formal or informal help had helped to relieve some emotional or psychological stresses for the young person.</p> <p>-More information provided to the family was seen as easier to plan the care of the father accordingly.</p> <p>-Positive coping mechanisms of children included: talking openly with friends or siblings, normalizing, distraction, having meals as a family, and taking it “one day at a time”</p> <p>-Negative coping mechanisms used by young people included: denial, drinking, smoking, self harming, and suicide intent.</p>

Nichols, Fam, Cook, Pearce, Elliot, Baago, Rockwood, and Chow (2013). When dementia is in the house: needs assessment survey for young caregivers.	14 young carers ages 11-18. 12 of the 14 lived with or were in strong contact with a mother, father, or stepfather with dementia (the remaining two cared for a grandparent with dementia)	Gain insight to needs and experiences of young people caring for person with frontotemporal dementia. Two focus group semi-structured interviews were conducted	None.	<p>-Positive coping mechanisms included: talking about memories or pleasant topics with the parent, family activities, extracurricular activities, and speaking with friends that were willing to listen to the child.</p> <p>- Most children reported that they did not wish to attend doctor's appointments for fear of being unable to cope with what they might hear.</p> <p>- Some children suggested that online support could be seen as helpful.</p>
Gelman and Greer, (2011). Young children in early-onset Alzheimer's disease families: research gaps and emerging service needs.	Father with YOD (age 50), a mother (age 40), a daughter (age 16) and a son (age 12).	Analyzed a case study of the family. The family was enrolled in six individual or group counseling sessions over the course of four months, received case management, and referrals for all family	None.	<p>-The daughter (16) was able to communicate her feelings openly with the family, was aware of the stresses of living with the father with YOD, and had been utilizing more support.</p> <p>- The son (12) was coping by doing school work and kept good grades as a result. However, he had stated that he felt "sad and</p>

		members. Analysis was based on the following theoretical frameworks: life-course perspective, family systems theory, and structural family therapy.		angry” much of the time. He had also gained an unspecified amount of weight, reportedly from all of the stresses and changes within his family.
Arends & Frick (2009) Without warning: lessons learned in the development and implementation of an early-onset Alzheimer’s disease program.	Group leaders of the Without Warning™ support group	Group leaders shared their experiences with running the support group. They also shared experiences of the people attending the support group for PWYOD and the family including children and spouses.	A seminar, 57 family meetings, 3 events for children less than 18 years of age, and social events for the family.	<p>For the author’s Without Warning™ support group the following were details from their best practice:</p> <ul style="list-style-type: none"> <li>-Meeting location that worked best for all members included an easily accessible building, well-lit room, and accessible elevators.</li> <li>-Ending meetings on time helped reduce the risk of people with EOAD wandering away and getting lost.</li> <li>-Best practices for group sessions for the person with EOAD included: prompting or cueing when necessary and having one</li> </ul>

				<p>consistent group leader.</p> <p>-Best practices for group sessions for the family, including the spouse and child, included: each small group having 8-12 members, little to no prompting necessary, and to receive support and to learn from other group members.</p>
<p>Svanberg, E., Stott, J., Spector, A. (2010). ‘Just helping’: children living with a parent with young onset dementia.</p>	<p>12 participants aged 11–18 who had lived with or were living with a parent with YOD at the time of the study.</p>	<p>Qualitative, in-depth interviews using grounded theory methodology with three quantitative measures including: the Recent Mood and Feelings Questionnaire (MFQ), the Zarit Burden Interview (ZBI-short), and the Resilience Scale (RS) to supplement the qualitative interviews.</p>	<p>None.</p>	<p>-Most of the children interviewed minimized their roles as carers and described their roles as “just helping”</p> <p>-Spending time with friends or at school helped distract them from their everyday stressors</p> <p>-Talking with other children who have had similar experiences would be helpful to the children interviewed.</p> <p>- The majority of children interviewed agreed that respite services would help relieve the</p>

				<p>burden of them and the family.</p> <p>- Both children were in the same household and had similar experiences and had received similar counseling, yet had different outcomes. It can be inferred that the need for individualized support, possibly by age, is needed for children.</p>
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